

Supplemental Material

ESTIMATING THE COST OF CARING FOR PEOPLE WITH CANCER AT THE END OF LIFE IN ENGLAND AND WALES: A MODELLING STUDY

In this supplemental material we provide a detailed description of how we derived the estimates used in the model and the search strategy and inclusion/exclusion criteria for the systematic review.

Health care resource use

Secondary care represents a significant proportion of the health care people receive at the end of their lives. The Nuffield study provides a robust overview of the secondary care services used by patients in the last 12 months of life, though resource use by cancer type was not available and was thus not reported (1). To estimate cancer specific resource use, we use publicly available hospital episode statistics (HES) data (2). Using these data, we estimate the number of emergency and elective admissions (planned and waiting list) and mean length of stay (Table 2). As there is currently no way to distinguish from HES data at what stage of cancer an individual admission occurred or whether it could be classed as end of life, estimates of the number of admissions are based on all those with each of the four studied cancers who use a hospital service, not just those at the end of life. Unit costs for hospital inpatient stays were estimated using NHS reference costs (3) for each of the cancer types (Table 3). No data were identified that would have allowed an estimate of the proportion of patients with any complications, major complications or no complications and so emergency admissions costs were estimated as an admission with major complications, while non-emergency admissions were estimated as having no complications. Accident and emergency visits were assumed to be evenly split between HRG codes relating to high and low cost investigations.

Guest and colleagues (4) found that in the end of life period, cancer patients accessed GP and district nurse services frequently (from 14.43 times for those with colorectal cancers up to 21.76 visits for those with prostate cancer) and this forms the basis of our estimate of primary care resource use. Guest et al also measured GP home visits, but found fewer than one visit per patient and so excluded these from their analysis. We follow this approach, as the impact on the overall cost will be low.

Social care resource use

The Nuffield Trust (1) study examined publicly funded home care services provided by seven local authorities. Across these seven sites, 15% of people received on average 1.12 hours of home care per day in the last 12 months of life. Patients with a diagnosis of cancer were found to have the lowest expected social care use relative to population norms for age and sex, using just 77% of the expected level of services relative to other users of social care.

In the Nuffield study (1), 6.4% of individuals in the seven local authority sites received care in a nursing home in the last year of life, with an average length of stay of 208.5 days – that is, 57% of the last year of life of 6.4 % of the population is spent in a nursing home. Again assuming that cancer patients use 77% of the expected level of service, we estimate that 4.93% of cancer patients will use nursing home care at the end of life. Additionally, it is necessary to adjust for the reduced length of time that patients are expected to live following a lung cancer diagnosis. We assume that patients use a proportionate number of nursing home care days as the average

individual. For example, for a lung cancer patient who survives for the median number of days (203) the estimate of days spent in a nursing home would be 115.96 (203×0.57). Based on 9.5% of all individuals receiving care(1) in a residential care home for an average of 220.1 days (60.3% of the last year of life), we estimate that 7.32% ($9.5\% \times 0.77$) of cancer patients will receive care in this setting, with the length of time again adjusted for expected survival by cancer type. Notably, patients in the model can only receive one of either nursing-home or residential-home care.

The Nuffield study (1) found that the coding of social care activity was inconsistent across different local authorities. Their analysis focused on those areas where a comparable subset of activities was recorded. This subset included the home, nursing and residential care described above, as well day care, direct payments and respite care. The latter three items were combined within a single category referred to as 'Other' services used. Only a small percentage of people (2.8%) received these other services at some point during the last 12 months of life, at an average cost of £2,698; for this analysis, we estimate that 2.16% ($2.8\% \times 0.77$) of patients access a mean of five units of 'Other' social care services.

Services excluded from the Nuffield analysis included meals, the cost of equipment or adaptations to homes, accommodation other than one's own home, nursing-home or residential-home and personal budgets. These services were excluded from their analysis on the grounds that recording between local authorities was inconsistent and that the expected cost for each of the services was low and was unlikely to have a significant impact on the overall results. Given the absence of any reliable estimate in the literature on how often such services were accessed we must also exclude an explicit accounting of these costs in our analysis. While we accept that this is likely to lead to an under-estimate of the overall cost of care, we agree with the conclusion of the Nuffield study that the total value of these services is likely to be small and therefore unlikely to significantly impact our overall results.

Care provided by charities

There are two key elements of care provided by charitable organisations to patients at the end of life that need to be considered. The first is care provided to patients in their home and is included in estimates of home care, as described above (it has not been possible to disaggregate charity provided care from other home care provision). The remainder of charity provided care occurs largely in hospices. Approximately 5% of all deaths occur in a hospice, of which 94% are patients with cancer (5). For this analysis we therefore assume that 4.7% of individuals will die in hospice. The average length of stay in hospice for a patient prior to death is 22.91 days, and the cost of hospice care is estimated at £419.20 per day (data provided by Marie Curie Cancer Care). In addition, hospices provide a range of inpatient, outpatient or day therapy care for patients who will not die there, but who nevertheless have palliative care needs. Outpatient hospice activity is estimated as 5.85 visits per person who used a hospice service, at £104.40 per attendance (estimate provided by Marie Curie Cancer Care).

Informal care giving

We estimate two key costs relating to the provision of informal care. The first is the cost of earnings foregone by informal carers who would otherwise be employed. Second, informal carers provide care that would otherwise have to be provided by state, private or charitable providers of care. Other costs include the costs of carer's allowance and the costs borne by carers for expenses such as travel. These are included as data allows.

There are many estimates of the number of people providing informal care and the value of that care to society available both in the literature and from special interest organisations. On the other hand, estimates of the number of people who have an informal carer are more difficult to identify. The Family Caregiver Alliance estimate that as many as 78% of people receive informal

care (6). By contrast, a second study from the US (7) found that the probability of receiving informal care for people who had received treatment for cancer in the past year was as low as 0.34. The only estimate found relating to the UK suggested that 'about three quarters' of people will receive care at home during the final year of their life, though no specific figure is given and no data is referenced (8). The disparity in estimates is difficult to reconcile; the UK estimate has no source and cannot be validated, while US estimates relate to a healthcare system that differs greatly from that in the UK. The most robust estimate of the number of people receiving informal care comes from the study by Hayman et al (7) and is used here.

Research for MacMillan Cancer Support published in 2012 examined the extent to which people with cancer received informal care (9). Although this did not focus on people at the end of life explicitly it provides the best available evidence at present. On average individuals in the study provided 15 hours of informal care per week. Hours of care provided increased when carers did not have to work in paid employment, with older patients and the unemployed providing more hours of care than those in work. We estimate that where an individual receives informal care then they receive on average 15 hours of care per week. The value of this care is estimated according to the hourly cost of home care of £17 as estimated in the Nuffield study.

Nineteen per cent of those carers who were in full-time employment indicated that caring had an impact on their working life, with 37% of these having reduced their hours of work. No estimate was provided in the Macmillan report about how many hours of work were lost. Using waves 1 to 18 of the British Household Panel Survey, we estimate that 59% of carers are typically in full or part-time employment and on average reduce working hours by 2.18 hours/week. The cost per hour of this lost employment is estimated according to the gross median wage in England - £501 per week, or £13.36 per hour assuming a 37.5 hour working week. A carer's allowance is available to those individuals providing 35 or more hour of care per week. The Macmillan study estimates that 16% of carers would be eligible for this, though only 5% of those eligible claim it.

The choice of method for estimating the costs of informal can have a significant impact on the results of a study (10;11) and so a clear statement of the approach used is essential. We consider the human capital approach to be the most appropriate method for this study. The human capital approach uses estimates of time lost to employment for those carers who must reduce employment to any degree. It also allows for an estimation of the value of informal care using a shadow price method to estimate what the cost of that care would be if provided through normal care commissioning mechanisms. This also allows for a value to be placed on the time of those who provide care, but are not otherwise in employment.

Resource use and survival time

The amount of resources used by an individual is a function not just of the nature of their illness but also the time they spend with that illness. Patients with a survival similar to the mean would be expected to use roughly the mean level of resources such as inpatient stays, outpatient visits, informal care hours and so on. Patients whose survival deviates significantly from the mean estimate would be expected to use different levels of resources, though it is not possible from the existing data to estimate a precise relationship for each category of resource use with expected survival. We assume that in most cases there will be a strong positive correlation (that is, as survival increases, resource use is expected to increase). To account for this relationship, resource use estimates are weighted by the ratio between the sampled expected survival for a patient in each simulation and the mean (expected) survival.

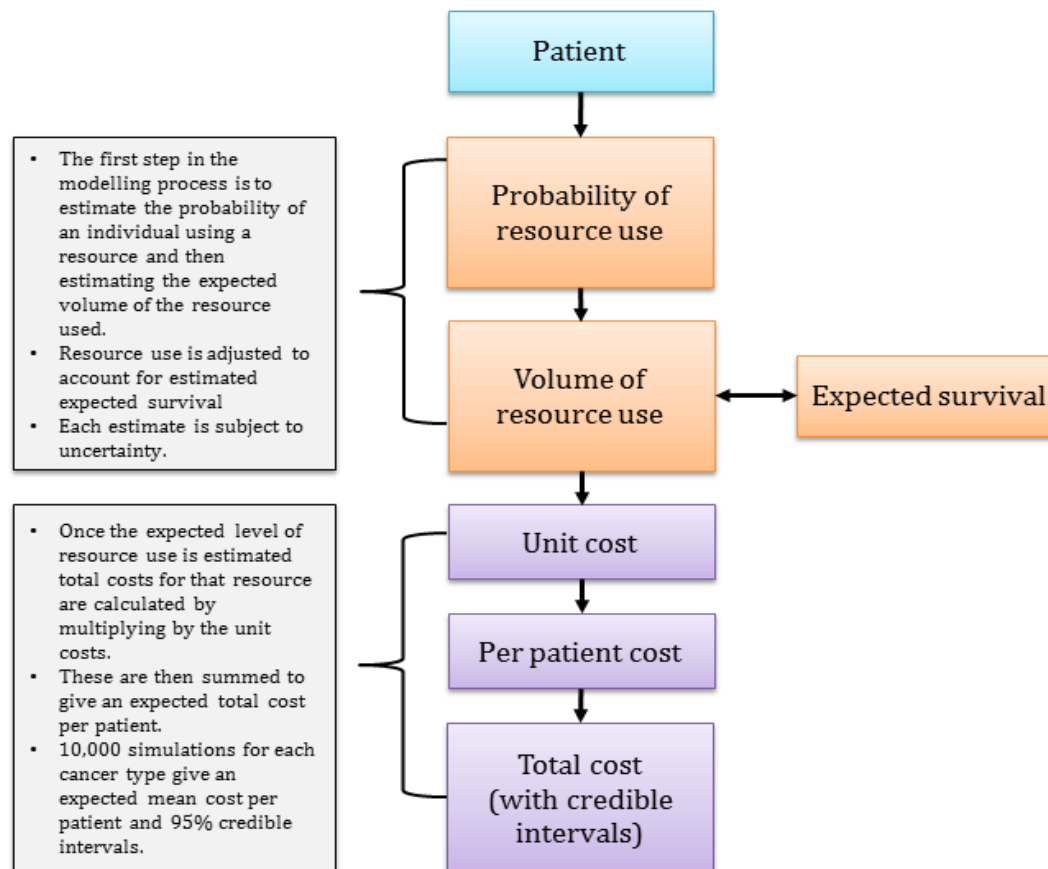
Sensitivity analysis

Both resource use counts and unit costs are subject to uncertainty, which will be modelled using a probabilistic approach, as described in the following section on sensitivity analysis. The expected mean cost per patient is then multiplied by the number of deaths per year attributed to

each disease. This gives the cost of providing care to people at the end of life for each of the four cancer types studied.

Overall costs are estimated as the sum of resources used multiplied by the unit cost of each resource. Each of these is treated in a probabilistic manner. Probability distributions are calculated for each resource use parameter in line with standard practice (12). Binomial events are modelled using Beta distributions, which are bound at 0 and 1. Counts of resource use are modelled using gamma distributions, bound at the lower end by 0. Where it has not been possible to estimate directly the parameters of each distribution, we have followed the approach of Briggs et al in setting $\alpha=1$ and $\beta=\mu$ (12). This is likely to lead to an overstatement of the true uncertainty of the model parameter and therefore our results. We consider this approach to be the most appropriate conservative method to addressing the problem of minimal reporting of measures of variance in the existing literature.

SM Figure 1: The modelling process.



Systematic review details

Search methods for identification of studies

Electronic databases

The following electronic databases were searched from 1990 to 1st April, 2015:

- Medline
- Embase
- PsychInfo
- EconLit
- NHSEED
- CINAHL

Grey literature was also searched, using two approaches. The first was the 'snowballing' approach based on citation tracking. The citations of studies included in the final review were traced and assessed against the inclusion criteria. The second approach was to conduct internet based searches using the popular general search engines as well as searching specific websites known to be potentially relevant (eg the National Audit Office, The Department of Health, NHS Evidence, Marie Curie Cancer Care, Macmillan Cancer support).

Search strategy

The following search terms were used to identify studies relating to palliative care.

1. Palliative care
2. Terminal care
3. Hospice care
4. ((hospice NEAR care) or (hospice NEAR caring))
5. ("end stage" or "late stage") AND (disease* or illness)
6. "dying" or "end of life"
7. "terminal* ill*" or "terminal stage"
8. "advanced NEAR disease*" or "advanced NEAR cancer" or "advanced NEAR illness"
9. palliat*

These terms were combined with filter terms for identifying economic studies using the 'AND' Boolean operator. The filter was based on that developed by the Centre for Reviews and Dissemination. An example filter for searching EMBASE is shown below:

1. economics/
2. exp "costs and cost analysis"/
3. economics, dental/
4. exp "economics, hospital"/
5. economics, medical/
6. economics, nursing/
7. economics, pharmaceutical/
8. (economic\$ or cost or costs or costly or costing or price or prices or pricing or pharmaco-economic\$).ti,ab.
9. (expenditure\$ not energy).ti,ab.
10. value for money.ti,ab.

11. budget\$.ti,ab.
12. or/1-11
13. ((energy or oxygen) adj cost).ti,ab.
14. (metabolic adj cost).ti,ab.
15. ((energy or oxygen) adj expenditure).ti,ab.
16. or/13-15
17. 12 not 16
18. letter.pt.
19. editorial.pt.
20. historical article.pt.
21. or/18-20
22. 17 not 21
23. Animals/
24. Humans/
25. 23 not (23 and 24)
26. 22 not 25

Selection of studies

Studies were assessed in two stages following standard systematic review methodology . In accordance with the defined inclusion criteria, citations were screened independently by two reviewers at all stages. The first stage was a review of titles and abstracts for potential relevance. Those studies judged to have potential to meet the inclusion criteria were retrieved for more detailed appraisal. Stage two was to review in detail retrieved studies for relevance and methodological rigour. Studies deemed to be relevant and that are methodologically sound were included in the final review. Where differences of opinion arose over the inclusion of a study at either stage, they were resolved by consensus by an independent third party..

Inclusion criteria

- Population defined by study authors as end of life
- Total care costs for end of life population of interest estimated
- UK setting
- English language

Exclusion criteria

- Economic evaluations of interventions or technologies. This study type only measures the costs of care relating to a particular intervention, and not the total costs of care for a population.

Assessing methodological quality

There is no accepted standard by which to assess the methodological quality of cost of illness studies. In the absence of an accepted standard, studies were assessed against a checklist developed for this review. This checklist has been developed with reference to a number of methodology checklists developed for assessing the quality of economic evaluations - the NICE methodology checklist as published in the 2009 edition of the Guidelines Manual; the Drummond/BMJ checklist for authors and referees of economic evaluations; and the checklist published by Evers (2005). The latter two checklists have been recommended for use by Cochrane. Although the criteria in these checklists were developed for assessing the methodological rigour of cost-effectiveness studies, many of the same principles (such as

discounting or the specification of analytical perspective) are highly relevant for cost of illness studies.

Language and publication type

Accepting the risk of not including potentially relevant results, studies were restricted to those published in English. It is not feasible, for reasons of time and cost, to consider studies in languages other than English.

There was no restriction on publication type, though reports or studies that did not satisfy the methodological criteria were excluded.

Reference List

(1) Georghiou T, S Davies, A Davies, M Bardsley. Understanding patterns of health and social care at the end of life. London: The Nuffield Trust; 2012 Feb 16.

(2) Department of Health. Hospital Episode Statistics, 2012-2013. 2014.

Ref Type: Online Source

(3) Department of Health. Payment by Results (PbR) tariff for payment of healthcare providers over 2013 to 2014. 2014.

Ref Type: Online Source

(4) Guest JF, Ruiz FJ, Greener MJ, Trotman IF. Palliative care treatment patterns and associated costs of healthcare resource use for specific advanced cancer patients in the UK. *Eur J Cancer Care (Engl)* 2006 Mar;15(1):65-73.

(5) Gomes B, Higginson IJ. Where people die (1974--2030): past trends, future projections and implications for care. *Palliat Med* 2008 Jan;22(1):33-41.

(6) Family Caregiver Alliance. Selected Long Term Care Statistics. 2014. 12-11-2014.

Ref Type: Online Source

(7) Hayman JA, Langa KM, Kabeto MU, Katz SJ, DeMonner SM, Chernew ME, et al. Estimating the cost of informal caregiving for elderly patients with cancer. *J Clin Oncol* 2001 Jul 1;19(13):3219-25.

(8) O'Neill B, Fallon M. ABC of palliative care. Principles of palliative care and pain control. *BMJ* 1997 Sep 27;315(7111):801-4.

(9) Macmillan Cancer Support. More than a Million. 2012 Jan.

(10) Joel E Segel. Cost of illness studies: A primer. 2006.

(11) Hirth RA, Chernew ME, Miller E, Fendrick AM, Weissert WG. Willingness to pay for a quality-adjusted life year: in search of a standard. *Med Decis Making* 2000 Jul;20(3):332-42.

(12) Andrew Briggs, Karl Calxton, Mark Sculpher. *Decision Modelling for Health Economic Evaluation*. 1 ed. Oxford: Oxford University Press; 2006.